PUBLIC HEALTH, WELFARE & SAFETY

Exhibit No. 1

Date 1-31-07

Bill No. SB162

DEPARTMENT OF PUBLIC HEALTH AND HUMAN SERVICES

BRIAN SCHWEITZER
GOVERNOR

JOAN MILES
DIRECTOR

STATE OF MONTANA

www.dphhs.mt.gov

DPHHS Testimony for SB 162
Senate Committee on Public Health, Welfare and Safety

Senator Weinberg, members of the committee, I am Jo Ann Dotson, chief of the Family and Community Health Bureau within the Department of Public Health and Human Services. We developed and strongly support SB 162, which moves Montana's public health newborn screening into the 21st century. This bill and the associated funding in HB 2 is an investment in the health of all babies born in Montana, and their families. This bill increases the potential for more babies to have a chance for as normal and healthy a life due to early detection and effective intervention of metabolic and endocrine disorders.

You've heard today about the human cost of too little, too late, or not at all. With newborn screening technology widely available today and with treatment options more clearly defined, Montana has the opportunity to prevent serious disabilities and premature death with relatively little monetary investment (as shown in HB 2). National data collected by the Centers for Disease Control and Prevention (CDC) demonstrate that the lifetime cost to society for a person with mental retardation in the United States is $1.1 million (adjusted to 2006 values). Not just PKU, but most of the metabolic disorders included in the nationally recommended newborn screening panel result in mental retardation if not managed adequately.

A few challenges with this bill:

- The expanded panel of tests will actually be in ARM 37.57.301
- Funding to support the follow up program is in HB 2.
- Expanding the panel of tests without developing a sound follow up program is not recommended, and is not good public health practice.
- Creation of this new program removes the role from the genetics program. It was put there 20 years ago when there were limited treatments or intervention identified for many of the conditions. Genetic counseling continues to be an important part of services provided to families.

Newborn screening must include adequate follow-up in order for the screening results to have the desired impact on health outcomes. We must have appropriate medical consultation for babies' primary care providers and families. We must track the babies with critical values from their screenings to be sure that the proper diagnostic tests are made as soon as possible and treatment begun. We must monitor the effectiveness of the services provided to families, and assure that the system of care is working for children and families in Montana.

We ask you to send a clear message that we are serous about preventing morbidity and providing early intervention for all babies born in Montana. Vote do pass on SB 162.

Clack, Sib

From: Clack, Sib
Sent: Tuesday, January 30, 2007 7:57 AM
To: Dotson, Jo Ann
Subject: Proponent testimony for SB 162

I will make copies for the Senate committee along with the other written testimony we have received.

From: sidzerda@aol.com [mailto:sidzerda@aol.com]
Sent: Monday, January 29, 2007 10:21 PM
To: Clack, Sib
Subject: Re: SB 162

I am writing in regard to the newborn screening bill. I spoke with Dr. Marian Kummer at the recent American Academy of Pediatrics meeting where we discussed this new bill. I strongly support the bill to require and support expanded newborn screening in our state. These tests which would be added to the newborn screen are in line with recommendations from the national standards for neonatal testing. Any one of these conditions can generate great medical expenses for the family and potentially threaten the lives of children affected by these disorders.

With the permission of the family involved, I would like to relate the detection and treatment of an illness in two children within the same family. The older boy, CM, now age 4, first started with illness at 6 months of age. Over the subsequent 3 months he had slowly worsening health despite many investigations into the cause of his illness. Finally at 9 months of age he was so ill that he needed emergency transport to Seattle Children's Hospital by plane. He then spent 2 weeks in the hospital. After his disorder was confirmed he returned home, but required many special services for the next year including occupational and speech therapy. He is now doing well. His younger brother JM, now age 2, had the expanded newborn screening. At 7 days of age his screening was found to be abnormal and he was started on appropriate therapy. He was never sick, has not required hospitalization for his disord er and is developping normally. When I asked his mother which of these situations was the better, her overwhelming support was for the early diagnosis. The preservation of JM's good health, the prompt treatment that he received were most important to her. However she does mention the great expense that went into the diagnosis of her older boy CM. Please listen to our state and national experts and assist Montana children and their families to get the timely help that they need. Sheila Idzerda MD